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Bodily Experiences and Repercussions of the Post-COVID-19 Condition on Activities of Daily Living

Experiências corporais e repercussões da condição pós-COVID-19 nas atividades da vida diária

Experiencias corporales y repercusiones de la condición post-COVID-19 en las actividades de la vida diaria

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Abstract: Introduction: The post-COVID-19 condition has been known for its prolonged effects on the physical, mental and functional health of those affected, directly impacting the performance of daily activities. The purpose of this study is to understand the bodily experiences of people with post-COVID-19 conditions and their repercussions on activities of daily living. Materials and methods: qualitative research conducted at the post-COVID outpatient clinic of a Teaching Hospital, with 20 participants, including 10 individuals in post-COVID-19 condition and 10 family members, between March to August 2022. The sample was intentional, and semi-structured interviews were carried out. Data were organized using IRAMUTEQ and analyzed through content analysis. Results: The persistent symptoms reported were fatigue, memory loss, respiratory difficulties, musculoskeletal and mental health limitations. These manifestations impacted daily life activities, such as eating, walking, performing personal hygiene, engaging in social interactions, and maintaining work-related connections. The need for frequent breaks, dependence on family support, and loss of autonomy were central elements in the experiences described, in addition to the re-signification of identity and roles, as well as family dynamics. Conclusion: The post-COVID-19 condition is not limited to clinical manifestations but reshapes how individuals perceive and construct their embodied identities. Care for these individuals requires multidisciplinary rehabilitation strategies that integrate physical, psychological, and social dimensions, promoting functionality, autonomy, and social inclusion.

Keywords: COVID-19; life-changing events; rehabilitation; post-COVID-19 syndrome; qualitative research.

Resumo: Introdução: A condição pós-COVID-19 tem se destacado por seus efeitos prolongados sobre a saúde física, mental e funcional das pessoas afetadas, repercutindo diretamente na realização das atividades da vida diária. Objetivo: Conhecer as experiências

corporais das pessoas com afecção pós-COVID-19 e sua repercussão nas atividades da vida diária. Método: Pesquisa qualitativa realizada no ambulatório pós-COVID de um Hospital Escola, com 20 participantes, dos quais 10 eram pessoas em condição pós-COVID-19 e 10 familiares, entre março e agosto de 2022. A amostra foi do tipo intencional, e realizou-se entrevista semiestruturada. Os dados foram organizados no IRAMUTEQ e analisados mediante análise de conteúdo. Resultados: Os sintomas persistentes relatados foram fadiga, perda de memória, dificuldades respiratórias, limitações musculoesqueléticas e de saúde mental. Essas manifestações impactaram as atividades da vida diária, como alimentar-se, caminhar, realizar a higiene pessoal, interagir socialmente e manter vínculos de trabalho. A necessidade de pausas frequentes, a dependência de apoio familiar e a perda da autonomia foram elementos centrais nas experiências vivenciadas. Além da ressignificação da identidade e dos papeis, assim como, da dinâmica familiar. Conclusão: A condição pós-COVID-19 não se limita a manifestações clínicas, mas transforma a forma como as pessoas percebem e constroem seus corpos identitários. O cuidado a essas pessoas exige estratégias de reabilitação multidisciplinar que integrem dimensões físicas, psicológicas e sociais, promovendo funcionalidade, autonomia e inclusão social.

Palavras-chave: COVID-19; acontecimentos que mudam a vida; reabilitação; síndrome pós-COVID-19; pesquisa qualitativa.

Resumen: Introducción: La condición post-COVID-19 ha destacado por sus efectos prolongados sobre la salud física, mental y funcional de las personas afectadas, repercutiendo directamente en la realización de las actividades de la vida diaria. Objetivo: Conocer las experiencias corporales de las personas con afección post-COVID-19 y su repercusión en las actividades de la vida diaria. Método: Investigación cualitativa realizada en el ambulatorio post-COVID de un Hospital Escuela, con 20 participantes, de los cuales 10 eran personas en condición post-COVID-19 y 10 familiares, entre marzo y agosto de 2022. La muestra fue intencional y se realizaron entrevistas semiestructuradas. Los datos fueron organizados en IRAMUTEQ y analizados con análisis de contenido. Resultados: Los síntomas persistentes reportados fueron fatiga, pérdida de memoria, dificultades respiratorias, limitaciones musculoesqueléticas y de salud mental. Estas manifestaciones impactaron actividades de la vida diaria como alimentarse, caminar, realizar la higiene personal, interactuar socialmente y mantener vínculos laborales. La necesidad de pausas frecuentes, la dependencia del apoyo familiar y la pérdida de autonomía fueron elementos centrales en las experiencias relatadas, además de la resignificación de la identidad, de los roles y de la dinámica familiar. Conclusión: La condición post-COVID-19 no se limita a manifestaciones clínicas, sino que transforma la manera en que las personas perciben y construyen sus cuerpos identitarios. El cuidado de estas personas exige estrategias de rehabilitación multidisciplinarias que integren dimensiones físicas, psicológicas y sociales, promoviendo funcionalidad, autonomía e inclusión social.

Palabras clave: COVID-19; acontecimientos que cambian la vida; rehabilitación; síndrome post-covid-19; investigación cualitativa.

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Introduction

The long-term impacts of the COVID-19 pandemic on the health of the population are gradually being acknowledged. It is understood that SARS-CoV-2 not only causes acute pulmonary complications but is also associated with persistent manifestations that compromise various organs and systems of the body. [1] In this context, the post-COVID-19 condition has gained prominence in health research, especially due to its negative impact on the quality of life of affected individuals.

The term "long COVID", translated into Portuguese as "COVID longa", was first used in May 2020 by British researcher Elisa Perego, when she reported her own experience with the disease. [2] It is acknowledged as the first term to be collectively adopted by people themselves through social networks to describe that condition. [2] Long COVID was identified from patient reports, and still exists mainly through them to this day. [3] In October 2021, the World Health Organization (WHO) introduced the official definition of "post-COVID-19 condition", highlighting it as an initial step towards improving the recognition and care of people in this condition, both in community settings and in health services. [4]

The post-COVID-19 condition describes symptoms that usually appear three months after the onset of coronavirus infection, last for at least two months, and cannot be explained by an alternative diagnosis. Symptoms may arise after initial recovery from an acute episode of COVID-19, persist from the onset of illness, or fluctuate or recur over time. [4] With a conservative estimate of 10 %, the prevalence of the post-COVID-19 condition in the world would reach around 75 million people, with approximately 4 million cases in Brazil. [5]

Several persistent symptoms have been identified in the literature, in both mild and severe cases of COVID-19 infection, the most frequent of which being fatigue, dyspnea, anosmia, sleep disorders, arthralgia, headache, cough, memory changes and impaired mental health. [6, 7] These prolonged manifestations resulted in loss of productivity, difficulties in returning to daily activities and work, in addition to requiring health resources for investigation, treatment, and rehabilitation. [7, 8]

The post-COVID-19 condition has a significant impact on people's lives, affecting both physical and mental health. A study in Italy showed that 87.4 % of patients had persistent symptoms, such as fatigue, dyspnea, and joint pain, which impaired their quality of life even 60 days after discharge. [9] Similarly, a study in Sweden revealed that 77 % of participants reported low life satisfaction, and 98 % of these attributed this deterioration to COVID-19. [7]

The post-COVID-19 condition transforms the way people experience and signify their bodies, causing detachment and emotional suffering. The experience of illness is not limited to a set of biological symptoms; it also involves narratives, meanings, and a reconfiguration of the subject's identity. [10] Fatigue, even in simple activities such as talking or performing household chores, redefines the limits of everyday autonomy. [9, 11, 12] Memory loss and difficulty concentrating destabilize confidence in one's own cognition, affecting not

only their performance in tasks, but also their perception of continuity of the self. [13, 14] Musculoskeletal limitations and difficulty in walking impose barriers to mobility, causing the body to be experienced as fragile, unpredictable, and dependent. [15, 16]

When taken together, these elements show that the post-COVID-19 condition is not limited to the presence of isolated symptoms, but alters the way the subject inhabits, recognizes, and signifies their body, producing experiences of estrangement and the need for readaptation. [17, 18]

The lack of conclusive diagnoses and the persistence of symptoms challenge the identity of those affected, who may feel like a burden to others and experience frustration, guilt, and loss of self-esteem. [18, 19] This process is not limited to recovery, but involves a reconstruction of identity and life trajectory, making a multidisciplinary approach essential in the care of post-COVID-19 individuals. [3]

With the increase in the population recovered from COVID-19, it is necessary to understand the health issues associated with the post-COVID-19 condition. The diversity of signs, symptoms and affected systems poses a clinical challenge, making long-term monitoring and rehabilitation with multidisciplinary teams essential to better recovery, with care tailored to the patient's clinical profile. [20, 21]

For these people, the full recognition of the post-COVID-19 condition as a distinct pathological entity, coupled with the validation of their experiential knowledge, goes beyond opening up ways to relieve physical and mental suffering. This recognition also symbolizes justice, reparation and an essential step forward in rebuilding their lives. [3]

Despite the advances in research into the post-COVID-19 condition, most studies have focused on biomedical, clinical, and epidemiological aspects, and fewer have considered the subjective experiences of those affected and their families from a qualitative approach. The study investigates how these people experience and resignify their bodies and daily lives in the face of the limitations imposed by the post-COVID-19 condition, contributing to the development of more humanized and integrated care strategies. In view of the above, this study aims to understand the bodily experiences of people in a post-COVID-19 condition and their repercussions on activities of daily living.

Materials and methods

Study Design

This paper reports on a qualitative study carried out between March and August 2022. Its development followed the *Consolidated Criteria for Reporting Qualitative Research* (COREQ) checklist. The research site was the post-COVID outpatient clinic of a teaching hospital that provides care to people in a post-COVID-19 condition.

Participants

Ten families participated in the study, comprising 10 individuals in a post-COVID-19 condition and 10 family members, totaling 20 participants. The selection of families was followed by the choice of a dyad consisting of a person in a post-COVID-19 condition and a family member, with the sample being intentional. To select them, the following inclusion criteria were applied to people with post-COVID-19 conditions: having received care at the outpatient clinic in 2022; being men and women aged between 18–59 years; having been diagnosed with COVID-19 at least three months ago; presenting at least two symptoms of the post-COVID-19 condition; being immunized with the COVID-19 vaccines; and being able to communicate verbally. The following inclusion criteria were used to select the family

members: being the family member with the greatest involvement in caring for a person with this condition; being 18 or over; being immunized with the vaccines for the virus; and being able to communicate verbally.

The researcher analyzed the medical records of patients at the clinic to identify potential participants. In cases in which the inclusion criteria were met, the researcher approached potential participants at the outpatient clinic, explaining the research and inviting them to participate. Eighteen patients were contacted by message or phone call, nine of whom agreed to take part, while the others did not take part for reasons such as readmission, withdrawal, family member unavailability, or lack of a response. After acceptance, the invitation was extended to family members, and interviews were scheduled according to the availability of both participants, taking place in their homes or online. A new participant was included through spontaneous contact and confirmation of the inclusion criteria.

Data Collection

Data were collected through semi-structured interviews with the family, the person affected by the post-COVID-19 condition, and a family caregiver, which were conducted after the research was presented and a Free and Informed Consent Form was signed. The interviews followed a guide with questions aimed at finding out about the person's experience with COVID-19, self-care practices, support network, feelings and sensations resulting from such illness, treatment and rehabilitation expenses. The questions also sought to understand, from the family's experience, the family's care and practices in this recovery and rehabilitation process. Eight face-to-face interviews and two online interviews were conducted, the latter through the university's Webconf virtual platform, at the request of the participants. The interviews were conducted by the first author of this article, at the time a master's student and nurse at a teaching hospital with experience in qualitative research. In addition to the principal investigator, a properly trained undergraduate nursing student participated in the transcription.

Data Analysis

The dataset for this research consists of 12 hours and 28 minutes of recorded interviews, transcribed verbatim in their entirety, totaling 163 pages of text.

The IRAMUTEQ software was used for the initial processing and organization of textual data. The text corpus corresponding to the ten interviews generated 2,563 text segments, of which 2,345 (91.49 %) were used for analysis using the Descending Hierarchical Classification (DHC) method. DHC sized text segments (TS) based on the most frequently used words. [22] The lexical classes generated by IRAMUTEQ served as indicators for the emergence of themes and the construction of analytical categories, which was then further deepened by a content analysis, conducted as proposed by Bardin. [23]

The analysis started with a full read-through in order to become immerse in the data and understand the whole. It then proceeded to a line-by-line reading, until codes were generated. The codes were compared, and text fragments were selected to identify themes, which later gave rise to categories. This process of building the categories involved a movement between the lexical structure provided by the software, successive in-depth readings of the full interviews, and the researcher's critical interpretation, supported by scientific literature. This approach made it possible to identify and deepen the relevant meanings that emerged from the participants' accounts.

Ethical considerations

This study was approved by the Research Ethics Committee of the Universidade Federal de Pelotas under CAAE 54365421.2.0000.5317. The Free and Informed Consent Form (ICF) was applied and, in order to maintain anonymity, the participants were identified using the abbreviation "P" for participant and "F" for family member, plus a card number, the letter "F" for female or "M" for men, and age, as in the examples: "P01F59y" and "F01F40y".

Results

Among those in post-COVID-19 condition, there were five men and five women. In terms of age, five participants were between 50 and 59 years old, three were between 40 and 49 years old, one participant was 37 years old and one was 24 years old. Six did not have a partner. Regarding the need for hospitalization, eight were admitted and, among these, six needed an Intensive Care Unit (ICU) and five received Mechanical Ventilation. The length of their stay ranged from 18 to 96 days. Considering the start of data collection, all participants had been diagnosed with the post-COVID-19 condition for more than nine months and were in the process of rehabilitation.

Among the family members, nine were women. In terms of relationships, the participants were daughters, mothers, spouses, stepmothers and cousins. As for age, seven were over 40.

"This is Something that Really Marks a Person": Bodily Experiences of People in Post-COVID-19 Conditions

The complications experienced by people with post-COVID-19 condition were: fatigue, shortness of breath, cough, chest pain, muscle pain, loss of fitness, lack of appetite, heart failure, difficulty concentrating, memory loss, dizziness, anxiety, and depression (Figure 1).

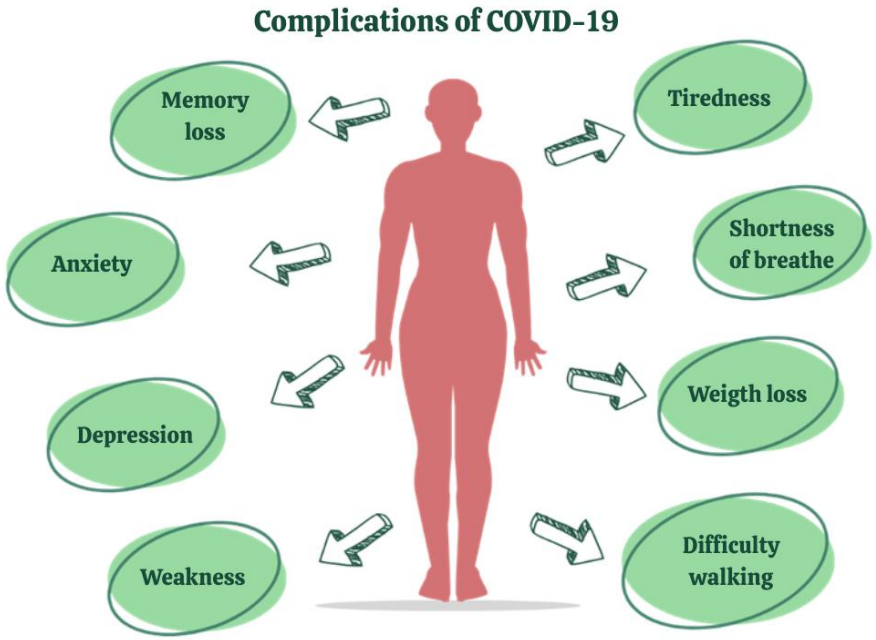

Figure 1. COVID-19 complications reported by participants. Source: Created by the first author.

Fatigue is one of the symptoms that persist for more than ten months past COVID-19 diagnosis. It is experienced both at rest and in motion, for example, when talking, walking, or performing certain household activities such as cooking, tidying up, washing the patio, etc. Other symptoms are sometimes associated with fatigue, such as "shortness of breath", "difficulty breathing", and coughing. These findings can be seen in the following statements:

> Sometimes I get tired. If I walk too fast, climbing those stairs there makes me a little tired. (P01F59y)
>
> When I left the hospital, I got tired after taking two steps. Today, I can go the whole day without oxygen. I walk, sometimes I go to my sister's house. I go slowly, but it's enough for me. (P02M53y)
>
> Because I've noticed that all I have to do is make a physical effort, go for a walk, for me to become breathless. It doesn't happen often, but when I exert myself physically, like when I lift weights, I get this shortness of breath. (P08F45y)

To cope with fatigue, people with post-COVID-19 conditions "rest", "stop" or take a break for certain periods of time to regain their "strength". Participants also report complications such as memory loss, difficulty remembering and recalling recent and past situations, and difficulty concentrating. "Forgetfulness", a term used by participants, negatively influences the development of daily activities, relationships with family members, and family life, as observed below:

> From time to time she forgets things. The other day she was saying that it's bad for her to cook when she's alone, because she puts the pan on the stove, sits here, and forgets about it. (F04M67y)
>
> She [wife] tells me things, at the time she tells me and in a moment I'm thinking, what did she say? I try to recall it in my mind, sometimes I get nervous and can't remember, I just can't. (P06M53y)
>
> The other day I went out and kept thinking, my goodness, did I lock the door? I was worried, but I had. And I look at the stove 30 times to see if I turned off the heat, the kettle, something. (P09F37y)

These complications were noticed by family members in their daily lives at home, leading them to develop certain practices to deal with them. These practices include time management, memory exercises, and reviewing certain activities, such as checking more than once to see if the door is locked or if the stove has been turned off, among others.

Other sensations and difficulties described by the participants were paresthesia, paresis, difficulty walking and even moving, using terms such as "loss of strength", "tingling sensation", "numbness", "weakness", as observed in the following findings:

> In reality, it was a period of adjustment. I couldn't steady my legs, especially my left leg. I couldn't steady it. So it took almost three months of treatment before I could walk normally. (P03M56y)
>
> I couldn't sit up, I was like a baby, I would fall to the side or fall backwards. When I bend down to pick things up like this, my legs feel weak; they're not very steady yet. (P04F59y)

> I have a lot of difficulty getting on and off the bus, I'm very slow, sometimes I even look like an old person getting off, very slowly, holding onto things [...], I feel like I don't have any strength in my body. (P06M53y)

Complications such as "loss of strength," "tingling sensation," "numbness," and "weakness" make it impossible for people in post-COVID-19 condition to perform activities such as walking, grasping objects, performing hygiene, socializing with other people in other spaces in the community, among others. This makes them depend on receiving help to carry them out, requiring them to adapt in time, in the environment and in their relationships with family members. As time passes and the illness process progresses, the body "recovers" its "normality".

Weight loss was reported by people in post-COVID-19 condition. It began at diagnosis, then hospitalization, and continued upon their return home. This complication resulted in "thinness", which led them to not recognize and perceive their own bodies. Some reported "not feeling like eating" and "loss of taste of food," however, it is clear that this complication occurred in participants who required prolonged hospitalization in the ICU.

> By the time I left the ICU, I had lost more than thirty kilos. I didn't even recognize myself on the bed. But I looked, I didn't recognize myself because of how thin I had become. (P02M53y)

> I was very, very, very thin, and I usually left the bathroom, took a shower and didn't even look at myself in the mirror. And I've always been someone who looks in the mirror twenty-four hours a day, that dresses up, and I didn't look for a long time. (P05M24y)

> I lost 30 kilos all in muscle mass, I was unrecognizable [...]. (P09F37y)

People in post-COVID-19 condition experience complications such as "crying", "fear", "anxiety" and "depression", noticed by family members, who step up to support them. These findings are represented in the following excerpts:

> But sometimes I get a bit like this [depressed, tearful], I remember that, but I'm here. I start whining, then I remember, but I'm here. Thank God I'm here, why are you crying? It's over now. But there's no forgetting it. (P01M59y)

> And emotionally, I feel he needs to be more careful, sometimes I notice he's more depressed [...]. (F02F27y)

> There are days when I see that he's very upset, he doesn't speak, he sleeps or he cries, I tell him to calm down, it'll pass, there's no point in getting ahead of yourself. (F06F49y)

Life has changed in countless ways for those dealing with symptoms of the post-COVID-19 condition. This means having to quit their jobs, cut back on expenses, choose from and/or give up activities they enjoyed before falling ill.

"I Haven't Returned to Work Yet": Repercussions of the Post-COVID-19 Condition

The participants of this study work as public transport drivers, app drivers, newly graduated agronomists, merchants, cleaning assistants, or school monitors, and for some of these people, complications such as difficulty walking and memory loss prevent them from

planning for the future and returning to work, as well as engaging in other enjoyable daily activities.

There is a gradual process of resuming life and carrying out activities that are similar to what they did before becoming ill with COVID-19, such as returning to work, which requires time to return to "normality".

> I don't see myself going back to work. It's complicated. And it's something I like to do [bus driver], I take the bus to go downtown, I wonder if I'm going to be able to do this, will I remember what I used to do? I feel tense like this. (P06M53y)

> I started working as a salesperson, and now, eight months later, I feel a lot of pressure. I don't know if I did the right or the wrong thing, [...], and I asked to leave the company so I could take care of myself, take care of my health, and that's what happened. (P07M43y)

> I used to be a cleaning assistant, and I still haven't returned to work, because I'm still unable to walk. I walk very slowly. And these things require me to walk quickly [...]. (P09F37y)

The time required for rehabilitation is another issue that clashes with the wishes of the families, and especially of the post-COVID-19 person. Some tried to return to work, but were unable to perform their usual duties, such as driving, meeting sales targets, and cleaning, or were unable to start their careers because they needed to take care of their health.

The failure to return to work, the absence from work caused by the complications of COVID-19, has caused financial difficulties for some families. This can be seen in the following accounts:

> We're trying to organize ourselves, the bills. Now I was saying to him, let's try to organize ourselves, we talk about saving money [...] and if we need fifty, sixty [reais] in a little while, I don't know, will we need it for medicine, something for him? Our lives have changed, they've changed overnight. (F06F49y)

> We have no benefits and the financial support was terrible [...]. They only gave him 1 month, you know? And the time he was off work, he was hospitalized, he didn't get anything. Imagine, we had a car, a house to pay for. (F07F46y)

"How Changed you Are": Rehabilitation of the Individual in Post-COVID-19 Condition

Returning home to be with family, as well as receiving visits from other relatives and friends, were important events for people in the post-COVID-19 period. Learning to cook, driving again, and playing with their nieces are some of the activities that participants do at home. Word search and crossword puzzles have been encouraged by their family to stimulate their memory, too.

> Of course I have to take care of myself, because my health is fragile, but I have to move around a bit, I have to gradually get my life back on track. Because through movement, by acquiring the movements that I can do I can have the stamina to do it. (P02M53y)

> I brought some books for him to do word searches, those crossword puzzles, to encourage memory, you know? But I tell him, you have to organize yourself little by little, change your routine, get out of this isolation [...]. (F06F49y)

Rehabilitation and readaptation at home can be a "slow" and "painful" process for some, while for others it can be "quick". Participants worried about whether they would ever walk again, stop using diapers, and recover their mental health, and family members showed support with words of encouragement and advice on how to get through this difficult time.

> And in that situation, will I be able to walk again? Will I be able to speak normally again? So it was a very painful process for us. [...] to get home and have to go through the process of readaptation, it's very complicated. (P03M56y)

> These days she [post-COVID-19 person] was complaining when am I going to stop with these diapers? And I say, look, you have to thank God that we're on the upside, because we've been through what we've been through and we're recovering. (F04M67ye)

> The other day he was saying that he didn't want to live anymore, that he was tired, and I told him stop it, it's just a phase that you'll pull through. (F06F49y)

It is clear that surviving COVID-19 is just the beginning of an unknown and probably long journey, and studies are required on the sequelae left by the disease, as well as the formation of a support network in the health system to treat and rehabilitate these people.

Discussion

In this study, people in a post-COVID-19 condition reported fatigue, dyspnea, memory problems, anxiety, and depression, among other symptoms. These findings are consistent with the literature on long COVID. [4] A prospective Brazilian study with 58 participants reinforces this evidence, showing a high rate of hospitalization during the acute phase and, after 15 months, persistence of complications such as fatigue, dyspnea, sleep disorders, and memory deficits, with a relevant impact on quality of life. [6] Even tasks considered simple became strenuous, forcing participants to reorganize their routines. As pointed out in the literature, [9, 11, 24] fatigue is persistent and impacts daily life.

Memory loss and difficulty concentrating emerged as complications of the disease. These reports corroborate the literature, [11, 13, 14] and here they are marked by insecurity and the need for constant family support.

Similarly, musculoskeletal limitations, expressed in terms such as "loss of strength" and "weakness", not only restricted mobility, but also produced a feeling of dependence and estrangement from one's own body. Thus, more than confirming previous findings, [15, 16] the results show how these bodily changes directly impact on the identity and autonomy of individuals, requiring continuous efforts to readapt in everyday life.

The experience of post-COVID-19 condition shows profound transformations in the way individuals perceive and signify their bodies. Reports indicate that the body, formerly an instrument of autonomy and functionality, is then perceived as a limitation, a "foreign body" that requires constant effort to adapt. This reconfiguration of the bodily experience directly affects the identity of those with post-COVID-19 condition, producing feelings of estrangement and frustration. For many, seeing themselves as thin, frail or dependent on diapers does not correspond to the image they had of themselves, which refers to the notion of loss of identity.

According to the interviews, weight loss was experienced with estrangement, which made some participants not recognize themselves in the mirror and avoid looking at their

own bodies. This perception of fragility and an "unrecognizable body" is connected to other complications described in the literature, such as changes in skin color and hair loss, which intensify the feeling of living in a body that is not one's own. [17] Similarly, prospective research in Italy identified significant weight loss in a significant portion of participants, reinforcing that COVID-19 can seriously compromise nutritional status. [25] However, the findings of this study go further by showing how these bodily changes are not restricted to clinical aspects, but also have repercussions on identity, self-esteem, and the way individuals relate to themselves and others.

Symptoms such as anxiety, depression, and sleep disturbances were cited by people in a post-COVID-19 condition, manifesting themselves in crying episodes, hopelessness and social isolation. These findings are consistent with the literature, which points to a high prevalence of psychological distress in this group. [26-28] In addition to the persistence of anguish and uncertainty about the future, studies also describe the fear of reinfection, relapses, and difficulties in reintegrating into the workforce, which can even lead to suicidal thoughts. [27, 28] Thus, the results found reinforce that adaptation to the post-COVID-19 condition involves a process marked by emotional suffering and loss of quality of life, demanding psychosocial support integrated into care.

The first meeting of people in the post-COVID-19 condition with family, neighbors and friends at home was described as "impactful", especially due to the visible physical transformations in the body. Those who have survived the infection have faced several complications, such as those already mentioned, which directly affect their daily activities, including personal hygiene, eating, getting around, social relationships, and employment status.

These complications vary in intensity and can hinder and delay the rehabilitation process, as well as alter routines, require adaptations in daily activities, and change family roles and relationships. In other words, these complications have transformed the lives not only of the people who have had the disease, but also of their families.

According to the participants' accounts, their body, once capable of carrying out everyday tasks, came to be seen as a barrier to be overcome. People affected by COVID-19 have to deal with the new limitations imposed by their bodies. What was once considered "easy" and natural, such as walking, lifting objects, performing daily activities or leaving the house, has become difficult or even impossible without the help of other people.

The findings of this study are consistent with research carried out in Sweden, which showed different trajectories after COVID-19: while some people reported a return to normality, others expressed deep suffering from no longer recognizing themselves. [18] This experience, often lived as a process of mourning, reflects the rupture between the "before" and the "after" of the infection, affecting not only physical functionality, but also subjective and social dimensions.

The persistence of symptoms significantly compromised the health and functionality of the participants in this study, with direct repercussions on their working lives. Many reported difficulties or inability to return to work, whether due to fatigue, brain fog or motor limitations, which resulted in delays, prolonged leave or the need for accommodation. These findings reinforce evidence that the post-COVID-19 condition often leads to reduced work capacity, with economic repercussions for families. [12, 17, 27] The experience of the participants shows that work was an indicator of recovery and return to normality, but also a space of frustration and stress in the face of persistent limitations. Thus, the results presented deepen the understanding of previous studies by showing that the impact on work

goes beyond the metrics of return or absence, involving self-perception of competence, self-esteem, and the reconstruction of life projects. [29, 30]

The reports indicate that the family plays a fundamental role in the rehabilitation process of the post-COVID-19 person, providing emotional support, encouragement and help in resuming daily activities. However, this support can also come with challenges, such as the need for family members to adapt to the new context of care. Many show concern about the ability of their loved one to resume their professional and social life, encouraging them to leave isolation and prepare for an eventual return to work.

The literature recognizes the importance of the family in the recovery process, especially in the early stages, in providing support for individuals to recover at their own pace. In addition, the family encouraged participation in rehabilitation programs, activities, and exercises. In some cases, family roles were adjusted, with redistribution of tasks among family members to ease the burden on participants at home, [29] corroborating the findings in our study.

The numerous complications caused by COVID-19 have brought to light the need for rehabilitation for this population group, creating a new challenge for the health system. In this context, post-hospital discharge rehabilitation began to be indicated as a strategy to improve the evolution and prognosis of patients, leading to the adaptation of specific programs to meet this demand. [16]

Strengthening rehabilitation services in the public network and expanding access to specific programs are fundamental measures to mitigate the impacts of the disease and give people in a post-COVID-19 condition the ability to return to activities of daily living, the job market and society.

In this study, people used services from the Brazilian Universal Healthcare System (SUS) network, such as primary care health units, outpatient clinics, the Home Care Service and Psychosocial Care Centers (CAPS), as well as specialized care both in the public and private sectors. Some participants reported that, upon discharge from hospital, they were referred to appointments at the post-COVID outpatient clinic and the Better at Home Program, while others were referred to care and rehabilitation by primary care health units.

In addition to physical rehabilitation, participants express concerns about regaining their self-esteem and the role they played in society. The fear of not being able to return to work or perform previously habitual activities suggests that the post-COVID-19 condition directly impacts the perception of identity and social belonging. Family and professional support play an essential role in this process, helping these people to rebuild their identities and resume their activities safely and progressively.

The full long-term impacts of COVID-19 on the health of the population are not yet known, nor is it possible to determine how long these people will need healthcare. Therefore, it is important to develop longitudinal studies to clarify these gaps, thus guiding public policies that allow the reorganization of health services in light of this reality. [16]

This study has some limitations. It was carried out in a single health service, located in a medium-sized city in the southern region of Brazil that has a post-COVID outpatient clinic integrated into the health network, which restricts institutional and sociocultural variability. In addition, this sample consisted of individuals linked to this service, which may exclude the experiences of people who have not been able to access specialized care or who have only resorted to private services. Moreover, the intentional sampling and small number of participants, typical of qualitative studies, despite favoring an in-depth understanding of

the phenomena, limit the representativeness of other realities, especially of more vulnerable groups.

Despite these limitations, the findings offer relevant contributions. People in a post-COVID-19 condition shared their own knowledge about their illness, built from the daily experience of symptoms and the reconfiguration of their routines. Thus, by highlighting the post-COVID-19 condition as an experience that is not only medical, but also existential and social, [3] this study broadens the understanding of the repercussions of the illness and provides support for the development of future investigations and more integrated and humanized health actions.

Final remarks

Surviving COVID-19 marks the beginning of a process of identity reconstruction and adaptation to a new reality. The experience of the post-COVID-19 condition leads to a resignification of life, highlighting reflections on capacities, limitations and the search to regain autonomy.

Given the physical, psychological, social and work-related impacts identified, it is essential to deepen knowledge about the prolonged effects of COVID-19 and develop more effective and personalized interventions.

The findings broaden the view beyond the biomedical model, highlighting the need to incorporate subjective and social dimensions into healthcare and reinforcing the importance of recognizing experiential knowledge as part of the therapeutic process and valuing it in the formulation of rehabilitation strategies and multidisciplinary patient management.

In this sense, this study contributes to strengthening more integrated health practices, taking patients' narratives into account. Finally, it highlights the need for public policies that expand access to rehabilitation services and ensure continuous follow-up, considering that the post-COVID-19 condition is not limited to a clinical condition, but represents a process of existential and social reconstruction for people.

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